# Child and Adolescent Special Populations Workgroup

Final Report and Recommendations
To the Commissioner of the
Department of Mental Health, Mental Retardation,
and Substance Abuse Services and the
Restructuring Policy Advisory Committee

August 2004

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# Membership—Child and Adolescent Special Populations Workgroup

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# **Final Report and Recommendations**

Child and Adolescent Special Populations Workgroup August 2004

#### Overview

In June 2003, the Commissioner of the Department of Mental Health, Mental Retardation, and Substance Abuse Services (DMHMRSAS) created the Child and Adolescent Special Populations Workgroup of the Department's Restructuring Policy Advisory Committee. This group was asked to develop sets of short term and long term recommendations on how mental health, mental retardation, and substance abuse services for youth and their families in Virginia might be strengthened. In August 2003, the workgroup forwarded a set of short term recommendations to the Commissioner for consideration. This final report outlines a set of long term recommendations that the workgroup feels will restructure and strengthen the current system for children and adolescents. Reports for specific populations are also included in this document.

## Background

In the 1980s under the direction of SAMHSA, the Center for Mental Health Services (CMHS), based on research concerning unmet needs of children with serious emotional disturbance (Knitzer, 1982), launched the Child and Adolescent Service System Program (CASSP). The CASSP model for service delivery promoted the concepts of the System of Care: child-centered and family-focused services that were community-based, culturally-competent, and integrated across agencies. Several programs of Systems of Care across the country have been funded by grants from CMHS.

In the late 1980s and early 1990s, Virginia began to take action to model certain components of the system of care as the basis for the Comprehensive Services Act.

Interagency collaboration at the state level prompted change in the funding system for children's services. The result is that pooled CSA funds are largely used to fund services for children in DSS custody or those who receive special education residential services. Other children, such as those with behavioral health problems living with their families and those involved in the juvenile justice system, are not guaranteed funded services and are served at the discretion of the 133 separate local government entities.

The Report of the Surgeon General's Conference on Children's Mental Health (2000) states that:

"The nation is facing a public crisis in mental health care for infants, children and adolescents...There is broad evidence that the nation lacks a unified infrastructure to help these children, many of whom are falling through the cracks. Too often, children who are not identified as having mental health problems and who do not receive services end up in jail. Children and families are suffering because of missed opportunities for prevention and early identification, fragmented treatment services, and low priorities for resources" (no page #).

# Important facts about children's service needs:

- Virginia's children
  - o 24% of the population of Virginia is under the age of 18 (Landers, 2001)
  - o 14% of healthcare funds is spent on children (Landers, 2001)
  - o 7% of MH expenditures go to children (Landers, 2001)

- Children with Serious Emotional Disorders (SED)
  - One in five children have a diagnosable mental health disorder (U.S.
     Department of Health and Human Services, Report of the Surgeon General,
     1999)
  - o One in 10 children has a serious emotional disturbance (Burns, et al., 1995)
  - 13% of preschool children in the US have mental health problems (Squires & Nickel, 2003)
  - 11% have a mental health condition causing significant functional impairment
     (Glied & Cuellar, 2003)
  - 62,000 children and adolescents in Virginia suffer from extreme impairment due to emotional disturbance
  - One third of children with a mental health disorder have been diagnosed with two or more disorders (CMHS, 1997)
  - 66% of juvenile offenders have at least one diagnosable mental disorder
     (Teplin, et al., 2002)
  - 94% of youth entering detention have a history of drug use (McClelland, et al., 2004)
  - Every night, 2000 children in the US wait in detention for community mental health services (Seltzer, 2004)

- Children of parents with mental disorders and/or substance abuse disorders have a 50% to 250% greater risk of developing mental health and substance abuse problems (SAMHSA, 2004)
- Children who have mental health problems are 4 times more likely to use and be dependent on an illicit drug than children who do not have a problem (SAMHSA, 1999)
- In 2002, 9% of US children live with at least one parent who abused or was dependent on alcohol and/or illicit drugs (NHSDA, 2003)
- Mental health problems are two to four times more prevalent among children in poverty (Glied & Cuellar, 2003)

#### • Current services

- 80% of children with serious emotional disturbance do not receive mental health services (Burns, et al., 1995)
- 92% of children and adolescents with serious emotional disturbance are served by three or more agencies (Glied & Cuellar, 2003)
- Hundreds of Virginia's children needing behavioral health services remain on waiting lists at CSBs (Voices of Virginia's Children, 2004)
- o Cross-agency coordination of care is difficult (Glied & Cuellar, 2003)

Children and adolescents with serious emotional disturbances are at increased risk of out-of-home placement due to the lack of consistent community-based services. These children often require intensive therapeutic interventions, parental support, medications, multiple agency involvement, inpatient hospitalizations, and residential treatment to address their pervasive problems.

## **Workgroup Activities**

The Child and Adolescent Special Populations Workgroup is comprised of advocates, public and private providers, state and local professionals in mental health, education, social services, juvenile justice, mental retardation, and substance abuse services. Parents and children provided input at select meetings and were encouraged to be involved at all meetings (see membership list on page 3 of this document). The Workgroup met 14 times from August 2003 through August 2004 to discuss the strengths and weaknesses of the current mental health, mental retardation, and substance abuses services systems in Virginia and to develop a set of short and long term recommendations for restructuring the current services delivery systems. Subcommittees were formed in the spring of 2004 and met multiple times to address specific subpopulations and issues including: juvenile justice; mental retardation; substance abuse; prevention and early intervention; and demonstration project models.

The Workgroup created a vision statement and identified key problems to be addressed in order to accomplish the vision. It reviewed several model and/or exemplary child mental health service systems in Virginia and across the country, including those in Milwaukee, El Paso County, CO, Philadelphia, New Jersey, Delaware, New Mexico, Connecticut, and the Georgetown University National Technical Assistance Center for Children's Mental Health System of Care Model. The group analyzed common elements that have made these systems successful. Below is a summary of the findings and subsequent

recommendations offered by the Workgroup. (All definitions related to this report are

included in Appendix F.)

**Vision Statement** 

The Virginia mental health, mental retardation, and substance abuse services system

will provide seamless access to prevention and intervention services for children and their

families that promotes the well-being of children and adolescents and reduces the incidence

and severity of behavioral health problems.

Keys to Accomplishing the Vision for Children with Behavioral Health

**Needs and Their Families** 

The workgroup agreed to the following as keys to accomplishing the vision:

• All children in need receive appropriate and timely services;

• There must be significant family and youth involvement at all levels of planning,

decision-making, and service delivery;

• There must be agency collaboration at state and local levels;

• There must be sufficient and flexible funding for services;

• There must be an adequate amount of services/treatments that are: evidence-

based/promising and/or best practices; child-centered; family-driven; culturally-

competent; strengths-based; and community-based;

• There will be sufficient funding for research on innovative interventions;

• There must be an adequate supply of qualified professionals;

• There must be seamless access, equity, and efficacy of services.

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# **Strengths of Virginia's Current System**

Virginia's system of behavioral health serves for children and adolescents has the following strengths:

- The CSA system has required collaboration/coordination for nearly ten years at the local and state level;
- CSA's values include many of the values of the system of care model;
- DMHMRSAS has a state board policy reflecting the values of the systems of care model developed in 1986;
- Local flexibility in service provision;
- Strong children's behavioral health advocacy and support;
- Parts of a continuum of care are in place;
- Strong universities with the capability to train child mental health, mental retardation, and substance abuse professionals;
- Excellent public inpatient facilities for children and adolescents;
- Recent formation of an Office of Child and Family Services in the state DMHMRSAS;
- Strong working relationship between DMAS and DMHMRSAS;
- Evidence-based/promising programs are in place in a few areas;
- The Commission on Youth has developed a website on evidence-based treatments for behavioral health disorders.

# Weaknesses of Virginia's System

The workgroup determined that the following items were weaknesses of the Virginia behavioral healthcare system for children and adolescents:

- Inadequate funding of behavioral health services for youth and their families;
- Children's services are fragmented across the state;
- The state legal code does not require the provision of behavioral health services for children and their families, which results in discontinuity in priorities across state agencies and localities;
- State agencies continue to be fragmented in their approaches to strengthen delivery of services to children and their families;
- Service provision is inconsistent and diverse across the 40 CSBs;
- The children's system of care in Virginia does not have a clear and consistent vision, identity, and set of priorities;
- Poor coordination among state and local agencies causes confusion for families,
   overlapping services, and increased cost to taxpayers;
- CSA does not sufficiently fund the needs of children with behavioral health disorders;
- Funding streams are not coordinated or sufficient;
- Children with behavioral health disorders who are involved in the juvenile justice system are not adequately served;
- Most youth with substance abuse disorders are not adequately served because substance abuse services are not sufficiently funded;
- MH/MR/SA services are not integrated with each other system wide;
- Although specific components of a comprehensive community-based System of Care
  have been identified, the extent of implementation varies significantly from community
  to community;
- There is insufficient funding for capacity building for community-based services;

- There is a lack of certified child psychiatrists and other child-trained professionals at many CSBs;
- There is a lack of consensus among service providers regarding how, which, and at what levels children's behavioral health services should be delivered;
- Children and families who receive behavioral health services funded by different funding streams receive different or no services;
- Services for children with mental retardation and severe behavior disorders are insufficient.

# Restructuring Public Child and Adolescent Inpatient Beds in Virginia

The membership feels strongly that public inpatient beds for children and adolescents were significantly reduced in the 1990s (see below). The membership also feels that there is no further need for bed reduction.

- Began in the early 1990s:
  - VTCC transferred from DMHMRSAS to VCU
  - o Eastern State Child and Adolescent Unit closed—1992
  - o Central State Adolescent Unit closed—1999
- Children's public beds dropped from almost 200 to 64 during the 1990s to current levels:
  - o Commonwealth Center for Children and Adolescents—48 beds
  - o Adolescent Unit at SWVMHI—16 beds

# **Workgroup Recommendations:**

The Workgroup strongly recommends that the state DMHMRSAS adopt the system of care model developed by the Georgetown University's Technical Assistance Center for Children's Mental Health and adopted by SAMHSA. The DMHMRSAS shall lead the statewide promulgation of this system of care model with other state agencies, families, CSBs, and other public and private providers.

The workgroup recommends four major funding priorities:

- 1. Four system of care demonstration projects outlined in Appendix E (\$2.5 million)
- 2. Parent/Youth Involvement Network (\$500,000 for the first year \$1 million for second year)
- 3. Behavioral health services provided by CSBs in detention centers during and after detention stay (\$3.5 million)
  - [There is a difference between the recommendations of the Juvenile Justice Subcommittee and the larger workgroup on lead agency for these services]
- 4. All resources in Virginia need to be maximized to build the capacity for behavioral health services that includes a comprehensive continuum of prevention, early intervention, and intensive therapeutic services
  - a. Increase Medicaid rates for day treatment services to \$150 per day
  - Add substance abuse services to the DMAS State plan and provide funding for treatment services for youth and their families with primary or secondary substance abuse diagnoses (\$5 million)
  - c. Conduct a rate study to expand community-based services in the state plan to include:

- i. Intensive Case Management Level System in CSBs
- ii. Parenting Education
- iii. Respite services
- iv. Behavioral Aides
- d. Training priorities are:
  - i. Systems of Care (\$500,000 for 5 regional and 1 state training);
  - Fund slots for university training of child psychiatry fellows and child psychology interns with payback provisions (\$60,000 per fellow, \$26,000 per intern).
  - e. Multisystemic Therapy (MST) and Functional Family Therapy (FFT) capacity building (\$2.5 million to include training and statewide licensure, and to oversee and fund local MST/FFT services)

# **Other System of Care Recommendations**

- The DMHMRSAS will recommend to the State Executive Council and the General Assembly possible Code, regulatory changes, and budget initiatives to support the revision and expansion of state and local systems of care.
- The system of care must include prevention and early intervention services for children and their families with or at risk of mental health, mental retardation, and substance abuse problems.
- 3. State agencies should continuously blend and braid funding sources to meet the needs of children and adolescents with MH/MR/SA problems and their families.

4. DMHMRSAS will support and expand its Office of Child and Family Services to assure that children's behavioral health services are prioritized and include all service entities related to children and their families.

# Additional recommendations related to increased funding

- Conduct statewide trainings on evidence-based, best practices, and promising treatments
  for children with behavioral health problems—statewide workshops, seminars, and crosscommunity trainings
- Cross-state and agency National Systems of Care model training (\$200,000 managed by DMHMRSAS with VACSB)

# **Recommendations not related to funding**

- 1. Encourage partnerships and collaborations among parents, all providers, and other stakeholders of children and their families with behavioral health problems
- Support the continuation of the Child and Adolescent Special Population Workgroup
  activities by merging the membership with the group established by Budget Item 330-F
  of the 2004 Appropriations Act
- 3. Support systems of care model including: 1) a coordinated, integrated, and individualized treatment plan; 2)families and surrogate families are full participants in all aspects of the planning and delivery of services; and 3) support a unitary (i.e., crossagency) care management/coordination approach even though multiple systems are involved, just as care planning structures need to support the development of one care plan (Pires, 2002)

- 4. Promote integration of services across MHMRSA disabilities by establishing policies that require services providers to conduct a single comprehensive intake addressing the areas of MHMRSA and developing a unified services plan and record
- Continue the dissemination of the Commission on Youth's "Collection" of evidencebased practices
- 6. Seek grant funding to enhance child and adolescent behavioral health services by establishing matching fund capacity through private foundations/corporations
- 7. Strengthen university/community partnerships to enhance child and adolescent behavioral health services
- 8. Encourage DMAS to "suspend" rather than "terminate" Medicaid benefits while children and adolescents are in a public institution including state hospitals, juvenile detention centers, juvenile correctional facilities, and jails.

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# Appendix A

# JUVENILE JUSTICE SUBCOMMITTEE OF THE CHILD AND ADOLESCENT SPECIAL POPULATION WORKGROUP July 30, 2004

#### **Report of Key Issues and Recommendations**

## **CO-CHAIRS:**

Joanne Smith, Director, Merrimac Center Middle Peninsula Juvenile Detention Commission President, Virginia Council on Juvenile Detention

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Dennis Waite, Ph.D. Chief Psychologist DJJ Behavioral Services Unit

#### **SCOPE OF ACTIVITIES:**

The target population of the subcommittee included children and adolescents who are the subject of children in need of services petitions or court orders; charged with delinquent offenses; or who have been adjudicated on a delinquent offense. The population included juveniles whose legal status is pre-adjudication or post-adjudication. These juveniles may be on probation or on parole. They may require placement in a secure or a non-secure environment, or they may be placed in the community. They may be in the physical custody of their legal guardians, the Department of Juvenile Justice Services, or a local juvenile detention center.

The input of parents and service providers was sought to inform this report in several ways: personal and group contacts by members of the subcommittee; invitations to send in written comments; invitations to attend and provide comment at public meetings scheduled for May 18, 2004 and May 27, 2004; and by survey interviews of parents who were visiting their children in juvenile detention centers. The names of the persons who addressed the subcommittee at the public meetings and copies of the written comments received are attached to the original printed report submitted to the Child and Adolescent Special Populations Workgroup.

#### **SUMMARY OF ISSUES and RECOMMENDATIONS:**

The provision of appropriate and timely treatment and services to juveniles with legal involvement and mental health, mental retardation or substance abuse (behavioral health) problems will be more likely to reduce future violence and recidivism than punishment in the absence of treatment. Adequate public funding is not available to provide sufficient behavioral health services for children and adolescents without behavioral health insurance, or with inadequate behavioral health insurance, in the Commonwealth of Virginia. Many juveniles with private health insurance may need many services, which are not covered by their insurance carriers.

Legislation would be introduced, with corresponding budget language, requiring that appropriate and timely behavioral health services and treatment be provided to juveniles and their families who are involved with the juvenile or the adult justice systems. Child serving agencies would collaborate to provide these services in an efficient, effective manner. Diversion and prevention would be included in these services.

Youth involved with the juvenile justice system should be designated as a priority population for services. Not only is the service(s) needed, but these youth have been identified as a threat to the community or themselves.

**ISSUE # 1** - Due to the lack of behavioral health services available to juveniles in most communities, the juvenile justice system is frequently used as the "de facto" mental health treatment system for this population.

#### **RECOMMENDATIONS:**

Amend the Code of Virginia, contingent upon funding, to require that each juvenile detention center (JDC) shall either (a) contract with public or private providers, or (b) employee clinical therapists, case managers, and other appropriate mental health staff, including child psychiatrists, proportionate to the census in each JDC.

Only skilled, trained persons would provide behavioral health services to youth involved with the juvenile justice system. Those treatment providers should use evidence based treatment approaches, when possible, in the community and in JDCs.

Case management and care coordination would link juveniles to services in the community and across placements.

<u>ISSUE #2 -</u> Child caring agencies frequently fail to acknowledge responsibility for youth involved with the juvenile justice system.

#### **RECOMMENDATIONS:**

The Secretaries of Health and Human Resources, Education and Public Safety would establish a process to ensure that all child serving agencies, at the state and local level, including CSBs, coordinate to develop and implement a continuum of services that includes assessment, treatment services, case management, transition services and consequences for youth involved with the juvenile justice system.

The Comprehensive Services Act categories of mandated/non mandated would be eliminated and behavioral health services <u>would</u> be provided to all youth involved with the juvenile justice system, regardless of legal charges or convictions, legal or physical custody, presence or absence of an Individualized IEP, or physical location.

<u>ISSUE #3</u> \_ Some juveniles held in JDCs and DJJ facilities need inpatient psychiatric treatment. These juveniles have a history of assaulting other juveniles and facility staff or have a history of setting fires. There are no public or private psychiatric beds in Virginia to provide adequate security, safety and supervision for these youth and to maintain staff safety.

#### **RECOMMENDATION:**

DMHMRSAS, in collaboration with DJJ, would provide a secure, forensic psychiatric unit for adolescents. The proposed adolescent forensic unit would be architecturally designed to adequately address the specific safety, security, treatment, educational, and recreational needs of these adolescents and also provide a safe treatment environment.

Adequate funding would be provided by the state to fund these services.

<u>ISSUE # 4</u> - Juveniles leaving detention or DJJ facilities experience problems transitioning to and accessing behavioral health services in the community. Barriers include the unavailability of willing treatment providers, long waiting lists and the low priority given to this population.

#### RECOMMENDATION

The Secretary of Public Safety would work with all effected entities to implement consistent discharge policies and procedures so that prior to discharge, the JDC or the DJJ facility housing the juvenile <u>would</u> pre-apply for applicable insurance programs or other available financial resources and link the juvenile to aftercare services in the community. These services would include in-home services and on call crisis service by specially trained staff.

Adequate funding would be provided by the state to fund these services.

<u>ISSUE # 5</u> – Youth involved in the juvenile justice system frequently do not have behavioral health coverage or adequate coverage for the services needed. Medicaid and some insurance companies stop coverage when the client is incarcerated.

#### **RECOMMENDATIONS:**

Juveniles who have not been adjudicated delinquent would continue to be eligible for Medicaid benefits or other insurance benefits so that they can continue to receive needed medications and treatment. DMAS, DMHMRSAS, and DJJ would clarify this point with federal regulators.

Pursuant to the May 25, 2004, Memorandum to State Medicaid Directors from Glenn Stanton, DEHPG, DHHS Centers for Medicare and Medicaid Services, entitled "Ending Chronic Homelessness" (copy attached), the Commissioner of DMHMRSAS will request the Virginia Department of Medicaid Services (DMAS) to immediately change its policies and procedures "to 'suspend' and not 'terminate' Medicaid benefits while a person is in a public institution or Institute for Mental Disease (IMD)". For all juveniles eligible for Medicaid benefits, when the juveniles are placed in a JDC, a DJJ facility, an adult jail, or a psychiatric facility, DMHMRSAS, DJJ and the Superintendents of the JDCs will request DMAS to immediately change its policy to suspend Medicaid benefits (instead of terminating Medicaid benefits) while juveniles are detained to minimize activation time after release from a secure facility or from an IMD.

Adequate funding would be provided by the state to fund these services.

<u>ISSUE #6</u> – There are children and adolescents in the juvenile justice system (a) whose primary needs are for behavioral health treatment and services, and (b) who do not pose a threat to the safety of the community.

#### **RECOMMENDATIONS:**

DMHMRSAS, in collaboration with the Office of the Executive Secretary of the Supreme Court of Virginia, the Virginia Council on Juvenile Detention, DJJ, and DCJS, would apply for federal demonstration project funds to identify these youth, establish a Memorandum of Agreement, and remove such children and adolescents from JDCs, and provide the needed behavioral health treatment and services to them in the least restrictive environment in the community. Adequate funding would be provided by the state to fund these services.

Diversion programs and early intervention programs for young offenders and first offenders would be established and funded to reduce the degree of penetration into the juvenile and the criminal justice systems.

<u>ISSUE # 7</u> – Juveniles with mental retardation and juveniles with multiple diagnoses whom the courts have judged to not present a risk to the safety of the public are occasionally placed into the juvenile justice system because communities do not have appropriate treatment, services, or placements to meet their needs.

#### **RECOMMENDATION:**

Regional treatment, services and placement programs for youth with mental retardation would be established to divert them from the juvenile justice system, when appropriate.

Adequate funding would be provided by the state to fund these services

<u>ISSUE</u> # 8 – Many communities provide no substance abuse treatment services for juveniles. The research demonstrates that the presence of co-morbid substance abuse and mental health disorders dramatically increases the risk for future violence.

#### RECOMMENDATION

Each CSB or JDC would provide substance abuse treatment services and integrated substance abuse and mental health treatment to adolescents in the community and in JDCs. The Commissioner of DMHMRSAS will request that DMAS modify its policies and procedures to reimburse qualified providers for substance abuse treatment services.

Adequate funding would be provided by the state to fund these services.

<u>ISSUE # 9</u> — Many juveniles in the juvenile justice system are unlikely to benefit from individual psychotherapy without the addition of adjunct treatment modalities. Research on successful intervention with this population reveals that intervention at the level of the family and community is critical to successful treatment

#### RECOMMENDATION

Whenever possible, evidence-based treatment modalities would be used to address the specific needs of juveniles, whether these interventions are individual, family, or group approaches. Such evidence-based treatments must involve the family or caretaker.

Adequate funding would be provided by the state to fund these services.

# Appendix B

# Child and Adolescent Special Populations Workgroup Substance Abuse Workgroup Final Report: July 2004

Chairperson: Martha Kurgans, DMHMRSAS

Members: Chris Young, Norfolk CSB; Pat Hill, Henrico CSB; Deidre Smith, Richmond Behavioral Health Authority; Jeanette Duval, DMHMRSAS; Carol Pollock, Virginia Department of Health; Joe Stallings, DMHMRSAS; Martha Stevens, Richmond Behavioral Health Authority; Madeleine Dupre, Commonwealth Center for Children and Adolescents; Denise Acker, Northwest CSB; Kathleen Dooley, Arlington CSB; Donna Dent, Blue Ridge Behavioral Health Authority; Parents, children and adolescents from the Norfolk CSB catchment area.

**Scope of Discussion**: Substance use and abuse affects Virginia's youth in myriad ways. We focused our discussion on the following topics: substance-exposed infants, adolescent substance use disorders, and the effects of parental (parents/caretakers) use on children and adolescents.

**Vision:** We envision a comprehensive system of care that includes prevention, early intervention, and treatment services across the continuum of substance use disorders for Virginia's youth and their parents and caregivers. The ideal system incorporates the following principles and approaches:

- Accessibility: promotes access via multiple doors and ensures that services are available regardless of client income and/or financial status.
- Cultural and linguistic competency: intervention strategies reflect individual client characteristics, including but not limited to, disability, gender, sexual orientation, developmental level, culture, ethnicity, age and health status.
- Evidence-based practices: services are consistent with best practice guidelines developed by the Substance Abuse and Mental Health Services Administration (SAMHSA) for the prevention and treatment of substance use disorders and cooccurring substance use and mental health disorders.
- Child centered and family-focused: services reflect the unique needs of infants, children, and adolescents and family members/significant others are fully involved in service planning and delivery.
- Integrated service delivery: substance abuse prevention, early intervention and treatment services are components of a broad individualized care plan that addresses the multiple needs of the client and family relative to health care, education, recreation, etc.
- Systematic approach to screening and assessment.
- Competency-based instructional programs for all system of care staff.
- Cost effective: services are provided at a reasonable cost to the Commonwealth.

#### I. General Systems Issues

#### • Barriers to care:

- o Cultural and linguistic barriers.
- o Access to funding.
- Lack of funding for services
- o Lack of transportation.
- Lack of childcare.
- o Staff shortages.
- o Lack of uniform diagnostic criteria for assessing co-occurring disorders.
- o Lack of staff trained in treating co-occurring disorders.
- Lack of uniform diagnostic criteria for assessing trauma and violence, effects
  of prenatal exposure to alcohol and other drugs, and family history for
  alcohol/other drug problems. Lack of staff trained in identifying and providing
  treatment in these areas.
- o Lack of uniform diagnostic criteria for assessing literacy.
- o Addiction counselor attrition.

#### • Recommendations:

- o Co-locate child and family services with addiction treatment services for the parent/caretaker.
- o Work collaboratively with local school departments to develop school-based treatment programs and student assistance programs.
- o Develop and implement system-wide plan for implementing evidence-based practices.
- o Develop counselor competencies for treatment of co-occurring disorders.
- o Provide incentives and tuition assistance for training and certification in addictions counseling and competency in treating co-occurring disorders.
- o Mandate and fund at least one full-time staff position for a child and family addictions specialist in every CSB.
- o Mandate and fund at least one full-time substance abuse case manager in every CSB to increase community outreach efforts.
- o Upgrade MIS systems and data entry procedures to ensure that all SA diagnoses are reflected in the data.
- o Establish a Governor's Council on Children and Youth to increase collaboration among agencies serving children and adolescents.
- o Sponsor statewide semi-annual meetings of child and family program staff to facilitate information sharing and systems change.
- o Provide multi-linguistic resources, including use of skilled bilingual and bicultural clinicians.
- o Increase services for the deaf and hearing-impaired community.
- o Implement strategic addictions treatment workforce development plan.
- o Maximize funding for treatment services
  - Lobby for Medicaid funding for substance abuse treatment and earmark state matching funds.
  - Increase enrollment in FAMIS

- Submit DMHMRSAS application for Access to Recovery funds for substance abuse treatment vouchers for adolescents for FY 2005.
- Work collaboratively with the Department of Medical Assistance (DMAS) to clarify procedures for accessing monies via the Early Periodic Screening, Diagnosis, and Treatment (EPSDT) process.

#### II. Substance-exposed infants

The work group was concerned about the lack of outreach and treatment services available to substance using women and their children. Infants exposed to substances in utero are "at risk" for congenital problems and other adverse health outcomes and psychological, developmental, and health risks extend beyond delivery. Although the Community Service Boards provide services for pregnant substance using women and their children and pregnant women receive treatment priority, relatively few pregnant and recently postpartum women are referred for and able to access services for themselves and their infants. Service providers across disciplines e.g. health, social services, mental health etc. lack the necessary skills and knowledge to identify and refer these women and their children to the appropriate services.

Substance using women have complex, multifaceted needs and can be difficult to engage in treatment. Barriers to care include the stigma associated with perinatal substance use, fear they will lose custody of their children, the lack of a full continuum of services that are gender specific and family focused as well as critical support services such as transportation and child care. Workgroup members recognized that many CSBs lack sufficient staffing to provide the level of outreach case management and interagency collaboration necessary to engage these women in services.

- Availability of services:
  - Expand Project LINK, which provides outreach and intensive case management services to substance using pregnant and parenting women and their children. Currently there are 14 8 Project LINK programs throughout the Commonwealth that serve 14 CSBs.
  - o Increase bed capacity for pregnant and parenting substance abusing women and their children. Currently, there are only 18 residential beds in three separate facilities for pregnant women and newborns and only one residential program that accepts substance-abusing women with children older than six months.
  - o Increase availability of parent education programs.
  - o Develop and implement specialized programs and services for pregnant substance abusing adolescents.
  - o Increase availability of services that promote mother-infant bonding.
  - o Ensure funding for opiate replacement therapy for pregnant opiate-dependent women and adolescents.
- Identification, screening, and assessment:
  - o Mandate service providers to refer all substance exposed children ages birth to five years for early intervention services.

- o Mandate service providers to include questions related to sexual activity and pregnancy in adolescent screening and evaluation instruments and interviews.
- Increase public awareness of the impact of prenatal substance use and availability of services for mothers and infants via public service announcements.
- o Provide annual training for CSB staff regarding prenatal substance use and its impact on infants and children.
- o Promote awareness amongst physicians and other health care providers about the effects of perinatal substance use on infants and children, treatment resources, Virginia's legal requirements and health care practice implications via distribution of brochures and other educational materials.

#### • Funding issues:

- o Identify and maximize available funding opportunities.
- o Educate physicians and other medical care providers about EPSDT (Early and Periodic Screening, Diagnosis, and Treatment) and encourage treatment providers to bill Medicaid for substance abuse treatment services.
- Work collaboratively with the Department of Social Services and other community agencies to access funding for treatment.

#### III. Adolescent Substance Use Disorders

The consensus of the workgroup is that there is a severe shortage of substance abuse treatment services for adolescents in Virginia. The shortage persists across all levels of care and is most acute for adolescents in need of residential services. It is very difficult to access public funding for a residential substance abuse treatment bed and impossible to secure a residential placement for an adolescent with a co-occurring mental health disorder, such as bipolar illness.

Furthermore, outpatient services tend to emulate the adult models of substance abuse treatment and do not adequately address the developmental realities of adolescence. Services promote a mistaken belief that the majority of adolescent substance users meet criteria for substance dependence. Our experience has shown that many adolescents do not respond to abstinence-based interventions and frequently drop out of treatment. We recommend a continuum of adolescent substance abuse treatment services that incorporates principles of motivational interviewing and matches treatment interventions with problem severity and stages of change.

We also encourage adoption of programs and practices that are "trauma sensitive". Research has shown a strong correlation between substance use and childhood trauma and violence. Methodology for assessing and treating childhood trauma and violence should be incorporated in adolescent substance abuse treatment at all levels of care.

#### • Screening and Assessment:

o Mandate routine screening for mental health <u>and</u> substance use disorders for every child and adolescent receiving services.

- o Require that all clinicians conducting intake interviews demonstrate proficiency in conducting substance abuse evaluations.
- Work collaboratively with school systems to design and implement screening, evaluation, and referral protocols.
- Ensure that screening and evaluation instruments and interviews routinely include trauma and violence indicators and questions relative to sexual activity.
- Encourage CSB staff to provide training to staff of community agencies relative to screening adolescents for substance use disorders and making treatment referrals.

#### • Treatment:

- o Ensure the provision of a full range of substance abuse treatment services throughout the Commonwealth. Services must reflect the unique needs of adolescents, incorporate evidence-based practices and include at a minimum:
  - Substance abuse education.
  - Outpatient treatment.
  - Intensive outpatient programs.
  - Detoxification and specialized services for opiate-dependent adolescents.
  - Residential treatment for substance abuse and for adolescents with cooccurring disorders.
  - Substance abuse case management.
  - Family education and therapy.
  - Transitional living opportunities.
  - Vocational services that do not require abstinence.
  - Access to alternative "recovery" or "sober" schools
  - Parenting training for parenting teens.
  - Incentives for treatment participation.

#### • Funding:

- Aggressively pursue additional grant funding opportunities for research related to substance use and abuse, treatment of co-occurring disorders and targeted capacity expansion.
- Work collaboratively with the Insurance Commission to develop and revise reimbursement standards for substance abuse treatment that reflect adolescent treatment needs

### IV. Effects of Parental (Caregiver) Use on Children and Adolescents

Over 6 million children nationwide (9%) live with at least one parent who abused alcohol or an illicit drug within the past year. These children are at "high risk" to develop mental health, substance abuse and other health disorders. The work group felt that early identification and intervention was critical to avert the development of more serious disorders and social consequence later in life. They also noted that early intervention was ultimately most cost effective to the state overall.

- Identification, screening, and assessment:
  - o Mandate service providers to include questions related to familial substance use patterns in child and adolescent screening and evaluation instruments and interviews.
  - o Ensure that the assessment and evaluation process for adults receiving services includes the children and adolescents in the family.
  - o Ensure that treatment plans developed for adults are family focused.

#### • Treatment:

- Ensure the provision of individual, group, and family therapy for children and adolescents affected by familial substance abuse and addiction.
- o Increase the availability of parent education programs for adults in recovery that address the impact of addiction on families.

# **Appendix C**

# **Prevention and Early Intervention Subcommittee**Bela Sood, MD and Brian Meyer, PhD, co-chairs

Members: Robert Cohen, CICFS/VCU; Pam Fitzgerald Cooper, DMHMRSAS; Joe Galano, College of William and Mary; Sue Geller, Wingspan, LLC.; John Morgan, Chesterfield CSB; Dick Repucci, University of Virginia; and Beth Wright, Centra Health/Virginia Baptist Hospital

In the early 1990's, Virginia enjoyed a reputation as a leader in progressive mental health policies. Investing in prevention initiatives with the long term goal of future savings and better population health was a priority. Subsequent administrations did not espouse that philosophy, and prevention efforts lost ground. Currently, behavioral health prevention efforts in the state are fragmented, and interagency collaboration is poor. The emphasis on prevention activities is uneven, with some localities actively embracing innovations in prevention activities related to children and others having virtually no prevention focus. Despite the inconsistency of prevention efforts around the state, a solid body of research demonstrates that the long term savings in improved population health makes prevention a good investment.

The following recommendations are not comprehensive. They identify two areas in which prevention efforts should be targeted as initial steps towards greater prevention activities in Virginia.

#### **Governor's Office of Substance Abuse Prevention**

#### Issue:

The GOSAP program is visionary and progressive. However, the state has not actively sought additional federal funds available for the program. There are pockets of excellence in prevention programs around the state that have sophisticated infrastructures in place. These programs could be replicated in other regions of the state

#### Recommendations:

- 1. Apply for more federal dollars to underwrite additional programs that espouse best practice prevention programs in Virginia.
- 2. Utilize existing evidence-based prevention programs in the state as templates to model prevention activities in other areas of the state.
- 3. Use prevention monies specifically for the population for which they are targeted: children and youth. Funds should not be allocated to other groups such as the elderly.

4. Move the GOSAP office under the jurisdiction of the Secretary of Health and Human Services rather than Public Safety, since prevention activities derive from knowledge of human development and health sciences, and therefore belong with health care.

#### **Juvenile Justice**

#### Issue:

Due to the disproportionate presence of learning disorders, emotional disturbances, and cognitive and behavioral disorders in the juvenile justice population, youth involved with the juvenile justice system are at high risk of academic failure, vocational failure, and consequent long-term involvement with the justice system.

#### Recommendations:

- 1. JLARC, in collaboration with DOE and DJJ, should study the relationship between the denial of eligibility for special education services, truancy, and placement in the juvenile justice system.
- 2. Since reading underlies most academic endeavors, juvenile detention centers and DJJ facilities should screen every youth who enters the juvenile justice system for reading problems as a required component of the intake assessment. Methods of educational instruction based on research in developing and implementing reading programs should be provided within juvenile justice facilities and in the community upon discharge. The state needs to provide adequate funding for these services.

# Appendix E

# **Demonstration Project Subcommittee Report**

Beth Rafferty and Brian Meyer, co-chairs

Members: Sandy Bryant, Central VA CSB; Pam Fitzgerald Cooper, DMHMRSAS; Margaret Crow, Voices for Virginia's Children; Jeanette DuVal, DMHMRSAS; Debbie Hinton, Richmond CSA Office; Pam McCune, State Office of CSA; Shirley Ricks, DMHMRSAS; Don Roe, Commonwealth Center for Children and Adolesents; and Bela Sood, VTCC/VCU

The System of Care Demonstration Project Subcommittee of the Child and Adolescent Special Populations Workgroup was created to develop the elements of a demonstration project for a restructured system of care for children and youth with behavioral health problems in the state of Virginia. The Workgroup decided that it did not want to draft an RFP, nor did it want to draft specific language to be put in an RFP, because both of those were beyond its responsibility and scope of authority. The Subcommittee was therefore given the task of identifying elements of a pilot project that could be implemented and evaluated and, if successful, form the basis of a model that could be adopted by communities around the state. The Subcommittee included representatives of DMHMRSAS, CSBs, CSA, the advocacy community, two children's psychiatric hospitals, and faculty from the Department of Psychiatry at VCU Medical Center. What follows is a summary of the Subcommittee's work

#### **Observations**

- There is an insufficient amount of money devoted to children's community-based behavioral health services; therefore, needed behavioral health services are not available to children and families around the state and too many children are placed in expensive residential placements
- While DMHMRSAS has responsibility for public behavioral health service delivery for children and families, the other state child-serving agencies (DSS, DOE, DJJ, VDH, and CSA and DMAS) share the responsibility for creating a structure that serves children and families as its core mission
- CSA as it is currently structured does not work. The behavioral health needs of large populations of children are not met (see prior CSA studies)
- No new studies of CSA are necessary, unless it is a study of how best to provide for children's behavioral health needs that includes CSA as part of a larger set of agencies
- Demonstration projects at a local level are needed to develop effective models of systems of care
- State level support and interagency cooperation are necessary to make the pilots work
- The interagency cooperation, any necessary restructuring, and the demonstration projects must be endorsed by the SEC and the Secretary of Education and directed by the office of the Secretary of DHHS
- The state needs to have a specific structure of systems of care that follows the structures and principles described by the Georgetown Center for Technical Assistance for Children's Mental health

- System change must include both administrative and financial changes
- Because localities operate differently, they need the freedom to choose among different models of systems of care within the state-designated framework

#### Proposal for a System of Care Demonstration Project

This proposal describes the elements of a system of care demonstration project. The project would be established in four sites around the state, including both urban and rural sites, for a period of 3 years. The estimated cost of the project is \$2.5 million per year for startup and evaluation.

#### <u>Services</u>

#### Minimum standards

- Immediate access to appropriate and recommended services
- Use of evidence-based, best practices, or promising practices and/or creative ideas for new and innovative approaches to integrated service delivery
- Outpatient psychotherapy is provided only by trained, licensed, and specialized clinicians
- Outpatient counseling provided only by qualified and/or license-eligible clinicians
- Authorization and approval of clinical services for children must be conducted by independently licensed clinicians specializing in child and adolescent treatment

#### Minimum services

- Screening and referral
- Diagnostic evaluations
- 24/7 crisis intervention and stabilization services, including psychiatric services
- Mobile and field response
- Crisis intervention and stabilization services
- Case management (per Medicaid regulations)
- Care coordination includes:
  - 1) consumer choice
  - 2) case management
  - 3) utilization review
  - 4) single unified treatment plan
  - 5) interagency collaboration
- Outpatient psychotherapy (Mental Health, Mental Retardation, and Substance Abuse)
- Intensive in-home therapy provided by licensed clinicians
- Day treatment
- Access to acute inpatient hospitalization
- Child psychiatry and psychopharmacology services provided by a board certified child psychiatrist (telemedicine is OK for monitoring but not for initial evaluation)
- Respite care (MH, MR, SA)
- Family support services
- Primary health screening provided by nurses
- Early Intervention-Part C
- Early Intervention-Mental Health

#### Enhanced Standards (desired)

- Single access point or any door access
- All psychiatric services provided in person
- Coordination of care for children with Axis III diagnoses (quarterly contacts at minimum)

#### Enhanced Services (desired)

- Shared single intake form
- Shared MIS system
- Brief partial hospitalization
- Treatment/therapeutic foster care
- Group Home
- Early intervention with at-risk children
- Prevention services
- Wraparound services
- 23-hour hospitalization
- Residential Treatment

#### Administrative Structure:

#### **Principles**

- Community-based system should be designed to meet the behavioral health-related needs of individual children and families
- All children with behavioral health problems have access to services
  - The locality will be responsible for arranging the provision of all behavioral health services in the continuum of care
- Local or regional collaboration exists between the major child-serving agencies
- Local CSBs will be the responsible agencies for the administration, funding, and care coordination of the demonstration program
- One treatment plan for family that ensures collaborative service delivery across all agencies
- The care coordinator is responsible to link the family to all necessary and appropriate services related to behavioral health needs across agencies
- Parent involvement and leadership in the development, decision-making, and evaluation structures and processes
- The system must deliver services to the parents, guardians, and primary caretakers of the child, which are necessary to ensure that the behavioral health care needs of the child are met
- Uniform evaluation measures determined by local evaluation coordinators who are members of a state evaluation team led by an independent contractor
- Evaluation money set aside; some goes to fund local evaluators; some to independent contractor
- State and federal monies will be allocated to the DMHMRSAS, which will pass through the monies to the local pilot project CSBs

- Monies will be blended and braided and used flexibly to meet the needs of children and families
- Money saved annually will be retained by the localities to reinvest in additional and enhanced behavioral health services for children, youth and families
- A system of care reinforces starting in and transitioning to least-restrictive services

#### Critical Elements

- Project structure must have one person responsible for all administrative functions (finance, UR evaluation, personnel, contract management, etc.), one person responsible for all clinical functions (care coordination, service delivery, integration of services across agencies), and one person responsible for evaluation
- Organizational structure includes a parent advisory board whose leader is part of the development and decision-making of the project
- Project will provide training and ongoing support to parent advisory board members to be effective child advocates
- Parents/caretakers will receive reimbursement for participation in project activities
- The CSB is the single organization/entity responsible for care coordination
- The CSB represents a coalition of agencies
- Treatment planning decisions are made by licensed clinicians
- Must include all minimum services and should include one or more enhanced services
- Multi-year plan to develop and implement all minimal services
- Needs assessments for child and family
- Uniform family treatment plan developed and implemented by a multi-agency team chaired by the clinical care coordinator
- No barriers for disability
- Access for persons to include transportation, child care, language, outreach services
- Multi-year plan to develop one door or any door access

#### **Funding**

Several different possible models were considered and reviewed. The proposed model is a hybrid of the others, combining the best features of each. (See "Child Behavioral Health/CSA Pilot Program/Conceptual Flow of Funding" on last page.)

#### **Proposed Demonstration Project Description**

- The DMHMRSAS will require that the local CSB designate that at least 25% of all new General Fund and Block Grant Funding for behavioral health services will go to capacity expansion of services for children and adolescents.
- The State CSA Office will forward the FY allocation to the local CSA Office.
- The State CSA Office will also forward to the local CSA Office 75% of the projected FY growth rate in that area.
- The local growth rate funds must be used for early intervention services.
- The State will retain 25% of the growth rate to use as a Risk Pool, and DMHMRSAS will use the money as match to access additional Federal funding.

- The local CSA Office will allocate funding to the DSS for regular foster care and placements in Emergency Shelters up to 30 days
- The local CSA Office will allocate funding to the LEA for classroom-based IEP services based on the highest number of children and the per child cost for these services over the past two years.
- The DSS and LEA will be responsible for providing these services to at least the same number of children at the specified case rate.
- The local DSS and the LEA can <u>not</u> access additional CSA funded services unless <u>prior</u> FAPT approval has been secured; they will be required to use local money to cover the cost of these services.
- The local CSA Office will use the same formula to allocate funding to the CSB to cover the cost of the behavioral health care services needed by CSA youth.
- The CSB will utilize licensed behavioral health specialists to complete comprehensive clinical evaluations on all assigned youth.
- The CSB will utilize the clinical assessments to authorize least-restrictive services that have been found to be effectively remediate the identified problems, and designate the projected duration and cost of the services needed.
- The services can not be accessed without the clinical authorization.
- The CSB, in collaboration with the CSA Office, will access emergency services for youth. FAPT approval must be secured within 14 days.
- The FAPT will staff all other cases, secure approved vendors based on the clinical authorization, and coordinate other needed interagency and community services.
- Families and agencies (e.g., DJJ) can access FAPT directly to request services for children.
- To move the child to less costly/clinically appropriate behavioral health alternatives as quickly as possible, CSBs will provide ongoing Utilization Review to these children, and will be responsible whenever possible for moving these children to more effective services, with the approval of the CSA Office within specific time frames.
- The CSB will be responsible for covering the cost of CSA funded behavioral health services accessed by the CSB without CSA approval.
- The locality will be able to apply to the State Risk Pool if:
  - The number of children in foster care increase over the established target number by 3% or more, or
  - The number of children in classroom-based IEP services increase over the established target number by 3% or more, or
  - The number of CSA children referred to the CSB for behavioral health services increase over the established target number by 3% or more, or
  - The clinical severity levels of the children increase as reflected on a standardized instrument measuring functional levels, causing a corresponding increase in associated costs (3% or more) from one FY to another.
- The State will establish a Risk Pool Governance Board composed of persons familiar with UR, clinical service issues, fiscal accounting, and economic forecasting.
- The locality is responsible for covering cost overruns not due to the reasons listed above.
- The local DSS, LEA and CSB will be allowed to retain any savings realized over the FY to reinvest in capacity building for children's behavioral health services.
- The local DSS, LEA and CSB are still responsible for providing services/expending funds for all other Federal, State, and Local required services.

• The project will take place over a 3-5 year time frame.

#### **Evaluation**

- Separate money set aside
- Each site has evaluation coordinator
- The DMHMRSAS will contract with an independent contractor for outcome evaluation
- Local evaluation coordinators are members of the state evaluation team, headed by an independent evaluator
- The independent evaluator will assemble and analyze data from all sites
- Before the RFP is released, elements of evaluation must be complete
- Program evaluation data will be used to determine clinical and cost-effectiveness
- The Evaluation report will be directed to the Secretaries of Health and Human Services and Education

#### **Application**

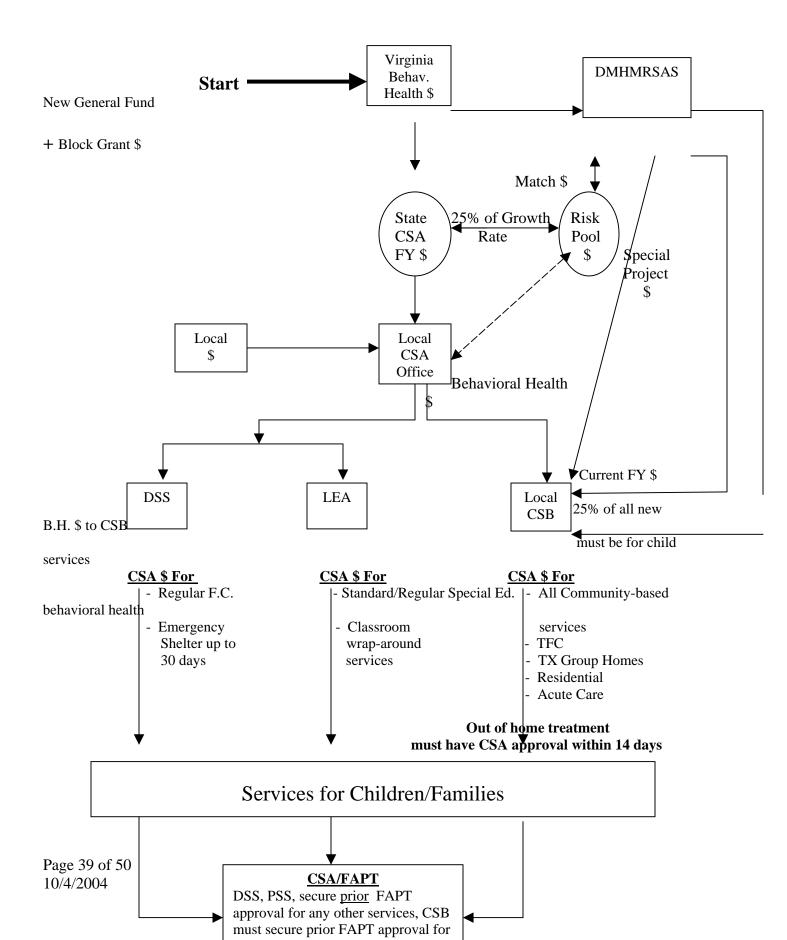
- Can be from a single agency representing coalition/jurisdiction or a community or multijurisdictional
- Includes signed letters of commitment and a signed memorandum of agreement that specifies new roles and responsibilities relating to participation in the demonstration project
- Demonstrates that applicants have a history of collaborating around developing integrated services for the target population
- Includes an organization chart
- Demonstrates needs for services
- Connects proposed services to demonstrated needs
- Outcomes are tied to identified needs
- Judges must sign the MOA
- Applicants will be encouraged to include a plan to create a separate 501(c)3 non-profit
  organization to maximize their ability to access public and private funding to further
  enhance the local system of care

#### **Unresolved Issues**

- What is the optimal state level structure that would best serve to meet the BH needs of children and families? (especially, roles of CSA and DMHMRSAS)
- What should be the role of local CSA (financial and clinical) in authorizing BH services?
  - State (DMHMRSAS) role includes TA prior to application/data due
- Timeline
- Quality control re: emergency services
- How many days does FAPT have to approve or deny services or to suggest alternative services?
- What code and regulatory variances are necessary to implement the pilots?
- Template for Memorandum of Agreement between agencies in a coalition

(See "Child Behavioral Health/CSA Pilot Program/Conceptual Flow of Funding" on next page.)

### Child Behavioral Health/CSA Pilot Program/Conceptual Flow of Funding



## Appendix E

## Mental Retardation/Developmental Disabilities Subcommittee Report Child and Adolescent Special Populations Workgroup Mary Ann Discenza and Barb Shue, Co-chairs

Members: Harry Gewanter, MD, Mary Cole, Cumberland Mountain CSB; Debra Holloway, ARC of Virginia; Leslie Anderson, DMHMRSAS; Kimberly Shepherd, DMHMRSAS; Pam Fitzgerald Cooper, DMHMRSAS; Chris Ruble, Whisper Ridge, Psychiatric Solutions, Inc.; Mary Beth Shutte, Henrico Area CSB; Leigh Menditto, parent; and Lace Coleman, Psychiatric Solutions, Inc.

#### **Issues:**

What are the barriers that prohibit efficient use of services? These barriers exist for all Virginians however, children with special health care needs and especially those with cognitive and behavioral problems serve as "canaries in the mine" (early warning system) to alert us to systemic issues within our society and its system of care.

<u>Continuum of services for MR children is not available</u>. School age children are particularly impacted. Some children cannot live at home, attend public schools, and have their needs met. What would it take to make a continuum of care?

- Reform
- Financial resources
- Providers availability

Systems of care model of service delivery

CSA intended as a system of care model of service delivery and has evolved into a reimbursement system for services

Medical Home model of care – American Academy of Pediatricians

Bureaucratic responses prohibit flexibility and creativity in problem solving and collaboration.

System is failure-based, crisis-oriented approach to chronic illnesses with acute exacerbations.

Accountability, responsibility, and funding of services are fragmented with implications that no one is accountable.

No appropriate continuum of services with smaller increments and not movement toward the highest level of care when community services don't work.

The system is not family-centered and it is not community focused with the ability for funding solutions that may in the long run be more cost-effective and successful than using traditional categorical medical and political model for funding services. There needs to be an appreciation of

the impact of this on the parents and the siblings and services need to be provided for the whole family. (Assistance based on medical diagnosis and political system that likes different cash boxes.)

There are parallel systems of care for "medical" and "behavioral" problems. Each system is insufficiently aware of the other and for this population (and in fact all persons) these divisions are artificial, duplicative and not appropriate for the needs of the children. Further, the knowledge, energy and time for accessing these systems is beyond the abilities of most families as well as the professionals who serve them.

<u>Access – Is the issue access to services or access to information or both?</u> The fact that there is a lack of portability of insurance inhibits access or continuation of services for families.

Retention and staff turnover is a serious problem and is an access issue for families.

Single point of information may be easier to promote than single point of access. Identifying an entity that knows about all resources for children and how to make it happen.

With cutbacks in funding, if the child is not Medicaid eligible, CSB doesn't provide services. Difficult to negotiate what is available for families who are middle income, private providers don't provide the same level of case management that CSBs provide. What would it take for parents to have easier access to services?

### <u>Integrating children with developmental disabilities into the appropriate service system.</u>

Children with MR do not fit into categories, the challenge becomes figuring out how to fund services for children without the type of disability becoming a potential barrier for accessing services.

System is not well defined so that families' ability to access services is difficult.

Case managers are not familiar with Medicaid regulations and therefore cannot provide information to families. Educating case managers to ensure that they provide correct information to families to ensure appropriate access to services.

**Services.** In order to access funding for services, providers are required to look at the child's diagnosis and not the child's needs. Is a better way to deal with the issue using functional assessment? What does the child need? For example, reframing the issue as one of the child needing social skills training rather than stating a child has behavioral problems.

The question still remains, who should do it and how do you get the services? Diagnostic labels do not apply to this population. It is necessary to come to agreement that a certain % of children have special health care needs (however we define that) and how are we going to meet the needs of these children.

Whatever services are necessary, what services does the child need, do we have the resources, and how do we match these two entities up? Crucial to this concept is the need for a care coordinator, what does this child need beyond the medical diagnosis, and how to access those resources.

There are parallel systems of care for "medical" and "behavioral" problems. Each system is insufficiently aware of the other and for this population (and in fact all persons) these divisions are artificial, duplicative and not appropriate for the needs of the children. Further, the knowledge, energy and time for accessing these systems is beyond the abilities of most families as well as the professionals who serve them.

Services need to be valued. This concept emphasizes the importance of offering training for enhancing skill level and competence of providers.

The system has to use resources most efficiently and not establish redundant systems that are not efficient or effective. There needs to be a model that looks at the needs of the child and values the child and the family and the providers and the services. For example, using CSA legislative concepts, how do we make this model work, or look at the IFSP (plan of care) model, as mechanisms for identifying family's resources, priorities, and needs to do service planning. Another example is Care Coordination for Children with Special Needs (Title V). This particular model offers care coordination through centers for children with special needs. Nurse practitioners work with families to assist them with accessing services.

System needs to learn from itself about what is successful in dealing with children's issues. According to DMHMRSAS State Board Policy: ".... is the policy of the Board that programs for children/adolescents and their families be specialized and flexible and be delivered by specially trained staff...to meet the individual needs of the child and family, in both institutional and community settings."

In order to access some services, families must relinquish custody to access services.

Services are not consistent across the state and this becomes an access and availability issue for families.

Virginia does not have a D/D system. Do we think that parents know enough to contact the CSB for services? Schools are not a good referral source for ensuring children with D/D receive necessary services. Easier for a child with an MR to access services because MR services are defined. D/D services are not clearly defined or readily available.

Accountability, responsibility, and funding of services are fragmented with implications that no one is accountable.

#### **Recommendations:**

- 1. Reframe the needs of children in the context of a chronic illness paradigm to mitigate the limitations of categorical eligibility and services, based on age, diagnosis, etc.
- 2. Research demonstrates that mental health and mental retardation issues are biologically based. To consider the effects of chronic illness on families and communities moves us toward a service concept that looks at the person and moves the system toward person-centered planning.
- 3. There needs to be sufficient funding as an incentive for providers to want to provide the needed services. Ensuring sufficient funding supports a core set of providers, sufficiently compensated to ensure a system of care and a back-up system to anticipate crises, manage the crises,

- supporting the primary caregivers. There needs to be recognition on the part of communities that these providers must be valued.
- 4. The DMHMRSAS in cooperation with the State Executive Council recommends and supports the development of a regional state-developed residential program for children with mental retardation and aggressive behaviors. The program would be developed in proximity to a state training center with collaborative support from the Commonwealth Center for Children and Adolesents. This program would provide in-state placements and services to children currently served in other states. The development of this regional placement would require CSA funds that are currently used for out-of-state placements.
- 5. To ensure families' access to insurance and to support the concept of portability of insurance, the Family Opportunity Act may serve as a model to help address this issue.
- 6. Care coordination is defined and someone is identified to provide care coordination.
- 7. To support staff retention, offer competitive salaries and access to benefit packages to ensure providers are available. The sub-committee recommends that the Commonwealth provide benefits directly or underwrite benefits for providers. It would be worth exploring to determine if this recommendation is a viable alternative to support providers. A model of support the state has with some of it's Medicaid Waivers that allows an individual-directed model of support and utilizes a fiscal agent with purpose paying staff hired by the individual, eliminating need for agency intermediary.
- 8. Improve and expand training to health care professionals for children's issues.
- 9. The best resource for services for children with MR should be the CSB. The challenge is how to integrate children with developmental disabilities into the appropriate service system. Most schools do not understand the complex needs of children with mental retardation; case management from the CSBs is the most appropriate system to serve children. The issue for the CSB; multiple case managers within the CSB, MH case manager, MR case manager, take the strength of the CSB and identify primary case manager to link the child to appropriate services and to ensure needs of children are met. Issue comes back to person-centered planning and access to any type of service a child with MR/DD would need.
- 10. The Commonwealth needs to actively promote EPSDT as a means for funding services for children. There are questions about what is available under EPSDT. Do pediatricians know about EPSDT? It is important to educate physicians about EPSDT. EPSDT is an untapped source of funding for services for children. What are the issues with accessing this resource? For children not meeting Medicaid eligibility to receive or other DSS and state supported insurance programs, there is little to no medical care coverage for children.
- 11. Title V and Care Coordination- may provide another funding stream for services for children. Need to re-frame as a chronic illness issue rather than trying to state it as a mental health need or issue. Principles used for dealing with any chronic illness apply to this population.
- 12. Recommendations from the Juvenile Justice subcommittee were generic and could be applied to children with special needs. The challenge becomes figuring out how to fund services for children in need without the specific disability becoming a potential barrier for accessing services.

Research demonstrates that mental health and mental retardation issues are biologically based. To consider the effects of chronic illness on families and communities helps us move toward a service concept that looks at the person and moves the system toward person-centered planning.

# Appendix F

# **GLOSSARY**

Accessible Services <sup>6</sup>	Services that are affordable, located nearby, and open during evenings and weekends. Staff is sensitive to and incorporates individual and cultural values. Staff is also sensitive to barriers that may keep a person from getting help. For example, an adolescent may be more willing to attend a support group meeting in a church or club near home than to travel to a mental health center. An accessible service can handle consumer demands without placing people on a long waiting list.
Appropriate Services <sup>6</sup>	Designed to meet the specific needs of each individual child and family. For example, one family may need day treatment, while another may need home-based services. Appropriate services for one child and family may not be appropriate for another. Appropriate services usually are provided in the child's community.
Assessment <sup>3</sup>	<ul> <li>Based on data from multiple sources</li> <li>Comprehensive</li> <li>Identify strengths, resources, needs</li> <li>Leads to care planning</li> </ul>
Best Practices <sup>6</sup>	<ul> <li>Promising – some positive outcomes</li> <li>Effective – consistently positive outcomes – strongly implemented and evaluated</li> <li>Model – availability for dissemination – technical assistance available from Program Developers</li> </ul>
Blended Funding <sup>9</sup>	Used to describe mechanisms that pool dollars from multiple sources and make them indistinguishable to produce greater strength, efficiency and/or effectiveness of dollars spent.
Braided Funding <sup>9</sup>	Used to describe mechanisms that pool dollars from multiple sources, but the funding streams remain visible to produce greater strength, efficiency, and/or effectiveness of dollars spent.
Capitated Rates 8	Reimbursement by insurance companies to care providers that has predetermined amount (cap of

	dollars for rendered services).
Care Authorization <sup>3</sup>	The structure for authorizing service and supports provision, initially and ongoing.
Care Coordination <sup>8</sup>	Brokering services for an individual to ensure that their needs are met and their services are not duplicated by the organizations involved in providing care.
Care Monitoring and Review <sup>3</sup>	The structure for monitoring and reviewing services and supports provision at the individual child and family level and at the population level.
Care Planning <sup>3</sup>	<ul> <li>Individualized decision making process for determining services and supports</li> <li>Draws on screening, assessment, and evaluation data</li> </ul>
Case Management <sup>6</sup>	A service that helps people arrange for appropriate services and support. The case manager coordinates mental health, social work, educational, health, vocational, transportation, advocacy, respite care, and recreational services as needed. The case manager makes sure that the changing needs of the child and family are met. (This definition does not apply to managed care.)
Collaboration <sup>8</sup>	A helping relationship between a family member and a professional in a reciprocal relationship in which the family and professional share power and responsibility. The relationship is grounded in the belief that the family of a child with an emotional disorder can be a resource to the professional and vice versa.
Community-Based Services <sup>8</sup>	The practice of having the focus of services as well as management and decision-making responsibility at the community level.
Continuum of Care <sup>6</sup>	A term that implies a progression of services that a child moves through usually one service at a time.  More recently, it has come to mean comprehensive services.
Crisis Residential Treatment Services	Short-term, round-the-clock help provided in a

	nonhospital setting during crisis. For example, when a child becomes aggressive and uncontrollable despite in-home supports, a parent can temporarily place the child in a crisis residential treatment service. The purposes of this care are to avoid inpatient hospitalization, help stabilize the child, and determine the next appropriate step.
Cultural and Linguistic Competence <sup>4</sup>	<ul> <li>For Individual – the state of being capable of functioning effectively in the context of cultural differences.</li> <li>For the Organization – a set of congruent practice skills, attitudes, policies and structures, which come together in a system, agency, or among professions and enable that system, agency of those professionals to work effectively in the context of cultural and linguistic differences.</li> </ul>
Cultural Competence <sup>6</sup>	Help that is sensitive and responsive to cultural differences. Caregivers aware of the impact of culture and possess skills to help provide services that respond appropriately to a person's unique cultural differences, including race and ethnicity, national origin, religion, age, gender, sexual orientation, or physical disability. They also adapt their skills to fit a family's values and customs.
Day Treatment <sup>6</sup>	Includes special education, counseling, parent training, vocational training, skill building, crisis intervention, and recreational therapy. It lasts at least 4 hours a day. Day Treatment programs work if conjunction with mental health, recreation, and education organizations may even be provided by them.
Early Intervention <sup>6</sup>	A process used to recognize warning signs for mental health problems and to take early action against factors that put individuals at risk. Early intervention can help children get better in less time and can prevent problems from becoming worse.
<b>Emergency and Crisis Services</b> <sup>6</sup>	A group of services that is available 24 hours a day, 7 days a week, during a mental health emergency. Examples include telephone crisis

	hotlines, suicide hotlines, crisis counseling, crisis residential treatment services, crisis outreach teams, and crisis respite care.
EPSDT (Early and Periodic Screening, Diagnosis, and Treatment) 1	<ul> <li>All eligible children are entitled to periodic screening services, including comprehensive physical examinations, and vision, dental and hearing screens</li> <li>All eligible children are entitled to any medically necessary service within the scope of the Federal program that is to correct or ameliorate defects, and physical and mental illness and conditions, even if the state in which the child resides has not otherwise elected to include that service in its state Medicaid plan.</li> </ul>
EPSDT <sup>2</sup>	This service is Medicaid's comprehensive and preventive child health program for individuals under the age of 21. EPSDT was defined by law as part of the Omnibus Budget Reconciliation Act of 1989 (OBRA 89) legislation and includes periodic screening, vision, dental, and hearing services. In addition, section 1905(r)(5) of the Social Security Act (the Act) requires that any medically necessary health care service listed at section 1905(a) of the Act be provided to an EPSDT recipient even if the service is not available under the State's Medicaid plan to the rest of the Medicaid population.
Evaluation <sup>3</sup>	<ul> <li>Discipline-specific, e.g. neurological exam</li> <li>Closer, more intensive study of a particular or suspected clinical issue</li> <li>Provides data to assessment process</li> </ul>
Evidenced-Based Practices <sup>3</sup>	Show evidence of effectiveness through carefully controlled scientific studies, including random clinical trials.
Family Support Services <sup>6</sup>	Help designed to keep the family together, while coping with mental health problems that affect them. These services may include consumer information workshops, in-home supports, family therapy, parenting training, crisis services, and respite care.

Family-Centered Services <sup>6</sup>	Help designed to meet the specific needs of each individual child and family. Children and families should not be expected to fit into services that do not meet their needs.
Governance 5	Decision making at a policy level that has legitimacy, authority, and accountability.
Home-Based Services <sup>6</sup>	Help provided in a family's home either for a defined period of time or for as long as it takes to deal with a mental health problem. Examples include parent training, counseling, and working with family members to identify, find, or provide other necessary help. The goal is to prevent the child from being placed outside of the home. (Alternate term: in-home supports)
<b>Independent Living Services</b> <sup>6</sup>	Support for a young person living on his or her own. These services include therapeutic group homes, supervised apartment living, and job placement. Services teach youth how to handle financial, medical, housing, transportation, and other daily living needs, as well as how to get along with others.
Individualized Education Program (IEP)  8	A federally mandated written individual plan of services for all children with disabilities who qualify for special education. It is developed jointly by parents and school personnel.
Individualized Services <sup>6</sup>	Services designed to meet the unique needs of each child and family. Services are individualized when the caregivers pay attention to the needs and strengths, ages, and stages of development of the child and individual family members.
Inpatient Hospitalization <sup>6</sup>	Mental health treatment provided in a hospital setting 24 hours a day. Inpatient hospitalization provides: (1) short-term treatment in cases where a child is in crisis and possibly a danger to him/herself or others, and (2) diagnosis and treatment when the patient cannot be evaluated or treated appropriately in an outpatient setting.
Least Restrictive Environment 8	An educational, treatment or living situation that provides appropriate services or programs for a

	child with disabilities while imposing as few limitations or constraints as possible.
Mandated for Services <sup>7</sup>	Those children/youth, who meet the relevant mandates for the provision of special education and foster care services and, prior to the enactment of CSA, were served by the funds placed in the pool.
<b>Promising Approaches</b> <sup>3</sup>	Show evidence of effectiveness through experience of key stakeholders (e.g., families, youth, providers, administrators).
Residential Treatment <sup>8</sup>	Live-in facilities that provide treatment and care for children with emotional disorders who require continuous medication and/or supervision or relief from environmental stresses.  *to include Therapeutic Foster Care (Special Populations Sub-committee)
Residential Treatment Centers <sup>6</sup>	Facilities that provide treatment 24 hours a day and can usually serve more than 12 young people at a time. Children with serious emotional disturbances receive constant supervision and care. Treatment may include individual, group, and family therapy; behavior therapy; special education; recreation therapy; and medical services. Residential treatment is usually more long-term than inpatient hospitalization. Centers are also known as therapeutic group homes.
Respite Care <sup>6</sup>	A service that provides a break for parents who have a child with a serious emotional disturbance. Trained parents or counselors take care of the child for a brief period of time to families relief from the strain of caring for the child. This type of care can be provided in the home or in another location. Some parents may need this help every week.
Screening <sup>3</sup>	First step, triage, identify children at high risk, link to appropriate assessments
System of Care <sup>3</sup>	Incorporates a broad array of services and supports that is organized into a coordinated network,

	integrates care planning and management across multiple levels, is culturally and linguistically competent, and builds meaningful partnerships with families and youth at service delivery, management, and policy levels.
Systems Change <sup>8</sup>	Making modifications in the way policy and procedures are made or services are delivered across multiple programs or agencies.
Transition <sup>8</sup>	The change from using children's services to using adult services, moving from one program to another, starting or leaving school, or other important life changes.
Wraparound Services <sup>8</sup>	The coordination of delivery of services to children and their families that is individually tailored to each case with the goal of keeping the family together in the community and being included in normalized school settings.

<sup>&</sup>lt;sup>1</sup> Surgeon General

<sup>&</sup>lt;sup>2</sup> Centers for Medicare and Medicaid Services

<sup>&</sup>lt;sup>3</sup> Pires, S. (2002). *Building Systems of Care: A Primer*. Washington D. C.: Human Service Collaborative.

<sup>&</sup>lt;sup>4</sup> Adapted from Cross, T., Bazron, B., Dennis, K., & Isaacs, M. (1989). *Towards a culturally competent system of care Vol. 1*, National Technical Assistance Center for Children's Mental Health, Georgetown University Child Development Center, Washington D. C. & NWICWA, (1993).

<sup>5</sup> Pires, S. (1995). Definition of governance. Washington D. C.: Human Service Collaborative.

<sup>&</sup>lt;sup>6</sup> SAMHSA's National Mental Health Information Center

<sup>&</sup>lt;sup>7</sup> Comprehensive Services Act For At-Risk Youth and Families Manual. Revised April 2003.

<sup>&</sup>lt;sup>8</sup> Glossary of Children's Mental Health Terms: Research & Training Center on Family Support and Children's Mental Health. Portland State University, Portland, Oregon.

<sup>&</sup>lt;sup>9</sup> U. S. Department of Labor. Office of Disability Employment Policy.